



October 28, 2015

The Honorable Gus Bilirakis
U.S. House of Representatives
Washington, D.C. 20515

Dear Congressman Bilirakis:

On behalf of the National Down Syndrome Society (NDSS), I am writing to express our support for H.R. ____, the Congenital Heart Futures Reauthorization Act of 2015. We commend you for your leadership in sponsoring this legislation. NDSS is the largest nonprofit organization dedicated to advocating for people with Down syndrome and their families at the federal, state and local levels of government. We are at the forefront of legislative efforts to improve the health and quality of life for people with Down syndrome so that they may realize their life aspirations.

Approximately one-half of all children with Down syndrome are born with congenital heart disease (CHD), most commonly Atrioventricular Septal Defect, Ventricular Septal Defect, Persistent Ductus Arteriosus and Tetralogy of Fallot. Although common defects can be repaired with a limited risk of death, CHD in people with Down syndrome during the early years of life has the potential to significantly affect cognitive function and overall health status later in life, and necessitates extensive medical intervention. In fact, neurodevelopmental outcomes among children with Down syndrome are known to be worse than those of typically developing children who have the same heart defects.

The Congenital Heart Futures Act, which was first authorized as part of the Affordable Care Act of 2010, has done much to improve the nation's surveillance, research, and education efforts to fight CHD. Reauthorization of the program is necessary to ensure sufficient funding for life-long research, and to continue making CHD research and surveillance a national priority. Furthermore, because CHD is so prevalent in people with Down syndrome, NDSS believes that increased federal research focused on diagnosis, treatment, prevention and long-term outcomes of CHD in the Down syndrome population could potentially provide important insights into the cause or causes of the disease and intervention strategies for the broader population.

Thank you for your leadership and support on this important issue. NDSS welcomes the opportunity to work with you to advance the reauthorization and funding of the Congenital Heart Futures Act.

Sincerely,

Sincerely,

A handwritten signature in black ink, appearing to read "Sara Hart Weir".

Sara Hart Weir, MS
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